

HIV/AIDS

WORK GROUP ON

HEALTH CARE ACCESS ISSUES

for Asian and Pacific Islanders

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U.S. Department of Health and Human Services
Public Health Service
Health Resources and Services Administration
Bureau of Health Resources Development

HIV/AIDS

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May 9-10, 1994

TABLE OF CONTENTS

OVERVIEW	5
OBJECTIVES	7
RYAN WHITE CARE ACT	9
BACKGROUND	11
SUMMARY OF PROCEEDINGS	13
IDENTIFIED BARRIERS TO CARE	15
Cultural Barriers	15
Other Barriers to Services	16
Structural Barriers: Policy and Funding	18
CASE STUDIES	21
Case Study #1	21
Case Study #2	23
Case Study #3	25
Case Study #4	27
RECOMMENDATIONS FOR TECHNICAL ASSISTANCE	29
RECOMMENDATIONS FOR POLICY	31
RECOMMENDATIONS FOR EVALUATION	35
APPENDICES	39
A-1: Categories for Asians and Pacific Islanders	39
A-2: Asian and Pacific Islander Service Providers	41
A-3: Meeting Agenda	43
A-4: Participants Listing	45

Overview

The Health Resources and Services Administration (HRSA), Bureau of Health Resources Development (BHRD), sponsored a Work Group on Barriers to HIV Care for Asians and Pacific Islanders (A&PIs) on May 9-10, 1994. Twenty-one Asian and Pacific Islander participants, as well as four Federal representatives, met to discuss issues related to barriers to the provision of HIV/AIDS services for A&PIs. The participants, from diverse backgrounds, experiences, and regions, were selected because of their knowledge of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, their participation in its implementation, and their involvement in identifying HIV care needs for the communities they serve. Several participants were people living with HIV disease. This group, however, only partially represents the broad regional, cultural, and socioeconomic diversity of A&PIs living in this country. Work group members shared a common commitment to reducing the barriers to HIV care for Asians and Pacific Islanders.

Objectives

This work group is one of a series of such meetings convened over a 3-year period by the Office of Science and Epidemiology (OSE) and the Division of HIV Services (DHS) within the Bureau of Health Resources Development. The primary objective of each meeting is to understand the barriers to providing HIV clinical and support services from the perspective of underserved populations and those who serve them. The insights about the availability, accessibility, and acceptability of specific medical and support services will assist the Bureau in evaluating the CARE Act and providing technical assistance to grantees to more effectively deliver services to people with HIV.

The work group's specific objectives derive from a concern that adequate HIV care is lacking in historically underserved communities. Within the A&PI populations, the diversity of ethnic groups and languages presents distinctive challenges in identifying effective strategies for delivering services to people living with HIV. Specifically, the work group members were asked to help the Bureau:

- Understand issues related A&PI access to HIV/AIDS care funded under the CARE Act;
- Propose and draft evaluation study designs; and
- Identify areas for technical assistance.

In addition, the work group was asked to identify as potential consultants health service researchers working on topics related to HIV/AIDS, members of affected populations, and individuals who deliver health care and support services. The group also was convened to develop methods and strategies to systematically assess whether and how the CARE Act is working to bring emergency relief to A&PIs affected and infected by HIV disease.

Ryan White CARE Act

In 1990, as a response to the critical need for basic medical and support services for people living with HIV disease, Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The CARE Act became law on August 18, 1990 and first received appropriations in November 1990. The principal objective of the legislation is "...to provide grants to improve the quality and availability of care for individuals and families with HIV disease..."

Titles I and II of the CARE Act are administered by the Bureau of Health Resources Development (BHRD), part of the Health Resources and Services Administration (HRSA). Grant funds, under Titles I and II, are awarded to the Eligible Metropolitan Areas (EMAs) most heavily affected by the HIV epidemic (Title I) and to all States and U.S. Territories (Title II). The grants are used primarily to fund ambulatory, outpatient, and community-based care, including both medical and social support services, for individuals and families with HIV and AIDS who are not insured or who lack critical services.

The CARE Act is founded on two basic tenets: (1) that people and communities affected by the HIV epidemic be included in planning and setting priorities, and managing the provision of care, and (2) that the comprehensive care needs of individuals with HIV and AIDS be met through a continuum of planned and coordinated services. Despite these tenets and the requirements of the CARE Act, BHRD recognizes that there are barriers that limit or prevent underserved populations from obtaining access to care. Many barriers to care existed before the HIV epidemic, but the crisis of the epidemic has underscored the need to remove them.

The effective delivery of HIV services has become an increasingly important activity within the public and private components of our nation's health and social service delivery systems. This increase in HIV services delivery, along with implementation of the Ryan White CARE Act, has focused considerable attention on a broad range of issues and made clear the urgent need to identify and reduce barriers to HIV services; develop technical assistance tools for service planners and providers; and evaluate the effectiveness and efficiency of HIV service delivery.

Background on Asian and Pacific Islander Communities and the HIV Epidemic

As is true with other underserved racial and ethnic groups, Asians and Pacific Islanders strongly feel the need for effective and accessible care. The National Commission on AIDS states in its December 1992 report, *The Challenge of HIV/AIDS in Communities of Color*, that “poor people of color are less likely to seek early treatment for HIV infection, are likely to have been less healthy when they contracted the virus, and are likely to have more advanced symptoms when they present themselves for treatment.” The Commission specifically recommends that “public health officials should work with researchers, health professionals, and community-based service providers to gain a better understanding of the role of cultural and socioeconomic factors in the transmission of HIV, the disease process, and access to care.”

Demographics

Asians and Pacific Islanders in the United States and its territories comprise two broad, separate and distinct categories. Within these two categories, the geographical distribution and diversity of distinct racial and ethnic groups is staggering. According to the 1990 Census, the category “Asian” includes 29 different groups, and the “Pacific Islander” category comprises 20 distinct ethnic groups. Collectively, members of these ethnic groups speak more than 100 languages and dialects. Significant cultural, socioeconomic, religious, and political differences exist both within and among ethnic groups. While many cultural themes are unique to a group, some common cultural themes reappear.

The A&PI population is estimated to be the fastest growing group in the United States with annual growth rates that may exceed 4 percent during the 1990s. By the middle of the 21st century, the A&PI population will grow to 41 million people, with birth rates expected to almost triple from 4 percent in 1992 to 11 percent in 2050. As of 1990, A&PIs made up 29.1 percent of the population in San Francisco (the largest minority group in the city), and 9.6 percent of California’s total population. In New York State, A&PIs comprise 3.9 percent of the population with the

largest concentration in New York City (7 percent of the city's population). In Hawai'i, the majority of the population are A&PIs, representing 61.8 percent of the archipelago's population. Texas, Illinois, New Jersey, Washington, Virginia, Florida and Massachusetts also have high concentrations of A&PIs.

Immigration, either to flee political turmoil and/or search for economic opportunities is the major factor in A&PI population growth in the United States. The number of A&PI immigrants is projected to exceed the number of A&PI births for the next 30 years. In total, more than three million A&PI immigrants and their descendants will be added to the U.S. population between the years 1991 and 2000.

Of the 441,528 cumulative cases of AIDS reported in the United States through December 31, 1994, 2,991, or about 0.7 percent, were among Asians and Pacific Islanders. The male to female ratio of AIDS cases is approximately 9 to 1. Of the total reported AIDS cases in the A&PI communities, 73 percent were among gay/bisexual identified men and other men who have sex with men, compared with 69 percent for all races. Among the pediatric cases, 48 percent were attributed to prenatal transmission from an HIV-positive mother and 39 percent were due to transmission of HIV through blood transfusions or blood products. Five percent of all AIDS cases in adult/adolescent A&PIs have resulted from injection drug use. For A&PI women, 45 percent of all AIDS cases were through heterosexual transmission, while 16 percent were due to intravenous drug use. As the A&PI population continues to be the fastest growing in the United States, careful attention to HIV rates of increase also must be closely monitored and care systems developed to accommodate HIV service needs among this growing population.

A&PIs are chronically underserved by the health care system. For the most part, HIV-related services have been culturally insensitive, linguistically inappropriate and systematically underfunded. To help understand the lack of services available to the Asians and Pacific Islander communities, the Health Resources and Services Administration convened a work group of policymakers, advocates, people with HIV and AIDS, experts in the evaluation of HIV services, and private and public service providers. Participants, selected for their diverse backgrounds and experience, were asked to identify barriers encountered by Asians and Pacific Islanders in accessing HIV services, to discuss forms of technical assistance needed to overcome those barriers, and to develop HIV evaluation questions.

Summary of Proceedings

The Asian and Pacific Islander Work Group met on May 9-10, 1994, and was moderated by BHRD staff member Moses B. Pounds, Ph.D., Office of Science and Epidemiology, and Steve Lew, Executive Director, Living Well Project (formerly, GAPA Community HIV Project). Work group participants were from varied regional, ethnic, gender and cultural backgrounds, including high/low incidence and rural areas (see Participant Listing - Appendix 4).

The work group session began with introductions and an overview of the Ryan White CARE Act and the Bureau of Health Resources Development, followed by a brief discussion of the agenda and suggested adjustments. Participants requested an opportunity to discuss constraints and challenges to delivering services to A&PIs living with HIV, and formed pairs to discuss and record their observations and experiences for later use in group discussions.

To promote a focused and optimal discussion of barriers to accessing needed services, participants asked to review case studies. These case studies provided a "real-life" framework that enabled participants to look more closely at everyday events in their respective work settings, and highlighted the facilitators and barriers to providing care and support services. The entire group then discussed these issues, identifying several common barriers and grouping them in separate categories: cultural barriers, structural barriers (policy and funding) and other barriers such as lack of services for women and inadequate youth services. This expedited the organization of discussion into the following three categories: technical assistance, policy and evaluation studies.

Later, work group participants divided into three groups based upon these categories. Subsequently, they separated into subgroups defined by the barriers, challenges and constraints identified earlier. Participants were requested to examine the barriers, and devise and recommend specific ways for HRSA to address these, including how the A&PI community can alleviate these barriers.

The entire group reached consensus on recommendations under the three categories of technical assistance, policy and evaluation studies. The following are examples of their recommendations, by category:

- (1) Technical assistance: capacity-building and institutional

development; culturally-appropriate training and recruitment of staff for A&PI service organizations; and updated data collection techniques; (2) Policy: a permanent A&PI HIV advisory work group; the inclusion of women and specifically, A&PI women, on decision-making bodies at Federal, State and local policy levels; and the prioritization of A&PI youth services; and (3) Evaluation: an assessment of the existing comprehensiveness of services for women, including conducting focus groups of A&PI women living with HIV; the development of guidelines for service delivery to A&PIs living with HIV and AIDS; and the development of a client survey to garner service-user feedback.

Arrangements were made to summarize and distribute the work group's recommendations for review by all participants, as well as other A&PI AIDS service providers. Reviewers' comments have been incorporated into a final draft for HRSA to use in developing technical assistance, policy and evaluation studies. A summary of the work group's deliberations will be distributed widely to participants, service providers, activists and other interested parties.

Identified Barriers to Care

During the facilitated discussions, work group participants identified barriers to effective HIV care among A&PI populations. Three categories emerged relating to culture, service provision, and policy and funding at Federal, State and local levels. The following barriers enumerated by the participants reflect their distinctive backgrounds and experiences, and therefore are not exhaustive. However, many A&PIs living with HIV confront these barriers as they seek adequate care.

Cultural Barriers

Diversity

A major barrier to HIV care delivery in the A&PI population is the lack of ethnic-specific and language appropriate prevention, care services, treatment (including access to experimental drugs) and information materials. There are several reasons for this: (1) more than 100 different Asian/A&PI languages; (2) inadequate Federal, State and local contracts for translators and interpreters; and (3) an inappropriate "one-size-fits-all" approach to program development. These factors contribute to alienation and dissatisfaction, which may lead to discontinuation of treatment.

Negotiating the Health Care System

The diversity of language and culture further exacerbates the use of health care services. A&PIs born outside of the United States, particularly those who are recent immigrants, are much less familiar with the American health care system and infrastructure than those who are U.S.-born or who have lived in the United States for a longer period of time. Patterns in utilization of health care services differ among various immigrant groups, yet this is not taken into consideration in designing programs and services for the immigrant population. For example, certain A&PI communities traditionally would use homeopathic care or other alternative treatments prior to or while seeking biomedical services.

Service Providers

The general public lacks an appreciation for and understanding of A&PI cultures, which may lead to bigotry or the unintentional

perpetuation of stereotyping. In health care settings, these attitudes can result in barriers to timely and appropriate HIV and related care. For example, the lack of linguistic capacity among service providers places inappropriate responsibility for interpretation on family members. This can cause undue strain within the close-knit, but distressed extended family network, a significant source of support for A&PIs living with HIV, as well as compromise the confidentiality of the client/patient. Despite the fact that families are a strong source of support, rarely are they incorporated into the care network by service and medical providers.

"A Gay Disease"

Like the general public, large numbers of A&PIs believe that AIDS exists only within the gay community. The stigma that HIV is a gay disease or limited to people with multiple casual sexual partners has an adverse effect on A&PIs seeking care, leading to denial of their disease and their need for care. The fear and embarrassment of being labeled gay may prevent or delay their accessing life-sustaining treatment that can promote full and enriching lives.

Other Barriers to Services

Lack of Services for Women

Because of the leadership of gay and bisexual men early in the course of the HIV epidemic and the epidemiology of HIV in the United States, the majority of existing AIDS service organizations (ASOs) is operated and organized by gay and bisexual men. This may cause discomfort and a lack of trust among A&PI women living with HIV, who may believe that services delivered in organizations identified as gay or staffed by gay, straight, or bisexual men, are not intended for them and may not meet their distinctive needs. As a result, these women may fail to receive the services they need because models of service delivery are not designed to meet women's needs.

Inadequate Youth Services

Similarly, A&PI youth living with HIV face limited care options. The majority of services are adult-focused and fail to implement specific and effective strategies to reach young people. In addition, the general lack of models of care for A&PI immigrant youth discourages timely diagnosis and treatment, so crucial in this population experiencing rapid HIV growth.

Inefficient Systems Within Agencies

Weak systems of coordination and integration undermine effective referral and follow-up care. To improve this, a common intake form to be used by all HIV service providers is needed to help reduce the time spent by providers on paperwork, and allow them more time to serve their clients. Non-English-literate A&PI clients find paperwork an obstacle to accessing services. Lack of common language leads to miscommunication and confusion between and among providers and clients, and frequently results in gaps in and possible duplication of services.

Clinical Trials

Some service providers use HIV clinical trials as a method of extending HIV service to their clients. However, clinical trials concentrate on a narrow and specific research topic, and usually do not cover the broad spectrum of illnesses related to HIV. Therefore, they are not equipped to accommodate the multiple concerns and health needs of A&PI clients seeking more comprehensive care. As a result, A&PIs with HIV are often disappointed and dissatisfied with the comprehensive care they receive through clinical trial sites.

Lack of Access to Alternative Treatment

Like many other people facing chronic, incurable diseases, A&PIs seek alternative therapies as an adjunct to biomedical care. Frequently, these therapies are beneficial and embedded in or related to their distinctive cultures, and are their first choice of treatment. This can create conflicts with medical and service providers, who often do not validate the use of alternative and non-biomedical treatments. Other reasons for lack of access include prohibitive costs and the perception of health professionals that alternative treatment is "primitive" or counterproductive. Because of these reasons, many A&PIs have less access to these alternative therapies than non-A&PIs. When barriers to A&PIs' use of beneficial alternative therapies are reduced, the effective use of biomedical care is more likely.

Insensitivity Among Providers

As reflective of the general public's attitudes towards AIDS, some A&PI medical doctors and service providers are reticent to seek HIV/AIDS training. They fear being identified as "AIDS doctors or care givers," a label that might "scare off" their patients. Such insensitivity compounds

the difficulties faced by A&PIs living with HIV, not the least of which is reducing their access to care.

Barriers Within AIDS ETCs

The federally-funded AIDS Education and Training Centers (AETCs) are the largest source (\$17 million annual budget) of HIV training for primary care providers, including physicians, dentists, nurses, physician's assistants and dental hygienists. Most work group participants were unaware of the AETC program, and the few who knew of it were unfamiliar with its structure. The perception is that the program lacks skills and knowledge about A&PI populations, both in strategies for recruiting participants who serve A&PIs, and in developing appropriate and effective training curricula.

Work group participants expressed concern that an opportunity for improving community-based organizations (CBOs) has been lost because AETC training is not directed to them. As a result, AETC training and information provided to clinicians is not responsive to the specific needs of local agencies that have the confidence of A&PI populations.

Participants also described the scope of AETC training as limited, and excluding the key components of A&PI HIV care delivery systems. For example, the curriculum covers only biomedical issues, neglecting approaches such as holistic, herbal, acupuncture and others especially meaningful to racial and ethnic-minority communities.

Structural Barriers: Policy and Funding

Lack of Technical Assistance

Work group participants characterized the funding application process for the CARE Act as complex and confusing for smaller CBOs for several reasons: unfamiliarity with the Federal HIV/AIDS programs; a lack of technical assistance from HRSA and other Federal agencies on grant application guidelines and requirements; little available information and assistance on effective grant writing and evaluation; and a process that has become political and overly bureaucratic. Additionally, in smaller community organizations, staff often lack the skills needed to access funding and resources. As a result, these smaller organizations grow at a very slow rate and experience a high failure rate, which compromises the ability of A&PIs to secure funding for A&PI-directed programs. This results in a bias toward established, mainstream

organizations whose resources enable them to produce proposals which are viewed as technically superior to those generated by A&PI-serving agencies.

Data Collection and Funding Levels

Because AIDS public policy is often driven by surveillance statistics of reported cases based on the majority population, A&PIs and other smaller racial and ethnic minority populations often are excluded from HIV care funding based on these statistics. This simplistic relationship between funding and case numbers neglects a major point: A&PI case management and HIV care require increased funding because of the labor-intensive language and cultural resources required. Additionally, because their case numbers are small, A&PI communities often are left out of funding and resource allocation policy discussions.

Limitations of Aggregating Data

Very often, local and State health departments do not gather AIDS surveillance data specific to A&PI populations and, when they do, A&PI statistics are not further broken down by ethnicity (more than 20 different ethnic groups comprise the A&PI population). The aggregating of racial and ethnic minority populations into the broad category "people of color" is an additional obstacle to directing funds to underserved individuals in A&PI communities. Currently, the 20 different A&PI groups and communities compete with other racial and ethnic minority populations for funding designated for "communities/people of color." To alleviate this, Federal agencies need to establish a formula for allocating a percentage of funding specifically to organizations serving vulnerable A&PIs.

Limited Infrastructure of A&PI Agencies

Although many A&PI AIDS service agencies have limited budgets and staff, they fill important gaps within the local medical and support services system. These small agencies focus their energies on delivering HIV-related care in culturally appropriate and linguistically competent ways to diverse underserved and vulnerable A&PI populations. However, their limited direct services budgets cannot support the full-time grant-writing staff necessary to enable them to compete with larger AIDS service organizations for scarce funds. Because sustaining rapid growth is difficult during periods of shifting funding priorities, small agencies must be careful not to overextend their staff and resources when attempting to expand their resource base.

Network of A&PI Service Providers

A&PI ASOs are growing at an uneven rate, hampered by their inability to compete successfully for funding with larger mainstream organizations. The result is an irregular network of A&PI AIDS service providers who lack the means for exchanging information among themselves. Information that is available, especially regarding developments in care treatments and therapies, is hard to access, especially true for those in remote or rural areas. As a result, providers do not receive timely and accurate information necessary to delivering quality care to their patients and clients.

Generally, non-HIV/AIDS organizations within mainstream Asian and Pacific Islander communities do not address HIV/AIDS as an important health, economic and political issue. A&PI AIDS organizations, therefore, are the primary conduit for raising HIV/AIDS awareness as an urgent health care and social issue. This responsibility for educating broader A&PI communities about AIDS further burdens the overextended resources of small A&PI AIDS organizations. As a result, AIDS remains a marginal social and political issue.

Lack of Policy Representation

A&PIs are not well represented on policy-making bodies such as the CARE Act HIV Planning Councils and Consortia and HIV Prevention Community Planning Groups of the Centers for Disease Control and Prevention (CDC). In many cases where A&PIs are involved in these bodies, they are neither knowledgeable of nor trained in CARE Act legislation and its implementation. This lack of knowledgeable representation exacerbates the limited impact of A&PIs on policy and funding issues that affect them. It also leads to the mistaken assumption that A&PI issues have been effectively addressed in the planning process.

Case Studies

To help the work group focus on the client's perspective, two case studies were presented prior to the three break-out group discussions. Danny Yu, Director of Client Services, Living Well Project, developed two composite case studies from various client case records and observations of several case managers. Two other case studies were added by participants to provide a framework for discussing facilitators and barriers to providing, accessing and receiving HIV care and support services. Further, these examples illustrate common patient/client experiences and health system responses. However, these case studies are not representative of the broad range of A&PI clients with HIV nationally.

Case Study #1

Mr. B, a 38-year-old first generation Chinese American gay man born in Taiwan, requested case management services at an ASO on the suggestion of a friend. Mr. B's first language was Mandarin Chinese. While he was proficient in conversational English, he expressed some concerns about his ability to understand technical information about health and medicine.

Mr. B had known of his HIV status for 3 years before seeking case management services. Originally, he came specifically to receive nutritional counseling to address his lack of appetite and weight loss. Up until the time he first came for services, his health had been relatively stable and he had no major infections. After addressing his initial concerns relating to nutrition and appetite, Mr. B's caseworker learned that he was satisfied with his HIV physician at a health maintenance organization (HMO). His caseworker also discovered that Mr. B did not always understand the medical information and treatment strategies explained by his physician, which Mr. B attributed to his occasional difficulty understanding his doctor's English. Mr. B also noted that he sometimes forgot to raise particular health concerns with his physician. Mr. B's caseworker offered to accompany him on his next physician's visit to see if he could be of any assistance in interpreting particular medical concerns and following up on any of the physician's advice presented during the visit.

After the first visit with his caseworker present, Mr. B's physicians agreed that it would be fine for the caseworker to continue to accompany

Mr. B to his appointments. In subsequent visits, the caseworker remained in the background helping, only when needed, to explain specific health and emotional concerns that were difficult to express in English. Before and after visits, Mr. B and his caseworker conferred to review his questions and concerns, and to prepare questions for his next visit. By the third or fourth visit, Mr. B began raising more concerns on his own, sometimes in English, and sometimes in Mandarin through his caseworker. As Mr. B identified more needs and concerns, his physician recommended that he meet with a nurse case manager after each visit. She reviewed with Mr. B the physician's recommendations and explained that she served as a primary medical contact for clients in case of emergencies. Through her, Mr. B was able to have questions answered by phone without having to wait for an appointment. The nurse case manager also acted as Mr. B's advocate within the HMO system. When Mr. B became eligible for SSI and Medi-Cal, she gave clear instructions on how he could access the HMO plan.

As Mr. B's illness progressed, his family became more involved in his care. His nurse case manager had developed a relationship with the family, and often collaborated with Mr. B's caseworker. Their combined information was conveyed to the family to assist them in caring for Mr. B. Throughout his illness, the caseworkers functioned as a team to meet Mr. B's needs within and outside of the HMO system.

Barriers to Care

1. Language and communication between A&PI clients and primary care physicians and providers;
2. The routine, cursory system of intake and processing sometimes did not identify client's linguistic and cultural needs. A sensitive, yet intensive, interview was needed to elicit sufficient detail; and
3. Navigation through and interpretation of the health care system was insufficient and failed to promote the client's level of comfort with the system.

Facilitators to Care

1. Translation and interpretation were essential services provided by the caseworker;
2. Willingness of physicians to work with a CBO providing client advocacy;

3. Effective communication and collaboration between and among providers and with family members;
4. Family provided essential emotional and material support as disease progressed; and
5. Lay referral networks provided entry into care system.

Case Study #2

Mr. J, a 33-year-old second generation Chinese American gay man residing in an midsize city, requested case management services at a local ASO for A&PIs. He had become disabled with chronic hepatitis and no longer was employed. Mr. J asked for help in running errands and with home food delivery because he was weak and unable to cook for himself. Mr. J also needed to find a new home because he had to vacate his apartment soon. Though he had a fairly well developed network of acquaintances, he had few close friends. Furthermore, Mr. J's family members, who knew he had AIDS, already were coping with another chronic illness in the family, and were limited in their ability to respond to his needs. His parents spoke only Cantonese, and no English. As Mr. J's health deteriorated, he developed chronic diarrhea and experienced major weight loss and nerve damage in his legs. He eventually moved into a residential facility for people with AIDS. His caseworker assisted him in applying for disability benefits and helped him enroll in an occupational therapy program where he pursued his passion for painting.

Three months after Mr. J began receiving services at the ASO, staff and volunteers began noticing uncharacteristic behavior. He frequently called in a panic complaining about the care he was receiving from friends, volunteers, and medical providers. He became intensely religious for the first time, and often stopped to pray while in the middle of conversations with friends and service providers. In one instance, he reported that John the Baptist was communicating with him. Prior to this behavior change, Mr. J had a CAT scan and neurological workup, the results of which were negative.

Accompanying Mr. J's unusual behavior were dizziness and difficulty walking. Several times, his friends or caseworker went with him to the emergency room at the HMO when he experienced dizziness and confusion. Each time, Mr. J was treated symptomatically and released. A crisis arose when he walked out of his room at the residential facility, and was found by a policeman taking all of his medication in a reported effort to kill himself. Mr. J was taken to the hospital.

A communications breakdown between the HMO physician and Mr. J's caseworker complicated his treatment. The physician had prescribed an anti-psychotic medication but did not order another CAT scan or MRI. Mr. J's caseworker called the HMO physician to discuss the possibility of AIDS dementia complex or an opportunistic infection such as toxoplasmosis or a CMV infection of the brain, and to suggest that another CAT scan or MRI might be appropriate. The physician decided not to order another series of tests, because the recently performed tests were all negative. He further stated that he would limit his communications concerning Mr. J's case to the family.

Up until this time, Mr. J's family had visited him once a week, but had not been involved in his medical care or social services. Because his parents did not speak English, Mr. J's physician communicated with his brother and sister, who did speak English. They were unfamiliar with HIV care and unable to discuss treatment options with Mr. J's physician. After speaking with Mr. J's caseworker, the family learned about the side effects of some anti-psychotic medications and that other medications were available for Mr. J's diagnosis. The caseworker also provided additional information to Mr. J's family about the clinical manifestations of HIV disease, particularly neuropsychiatric disorders. Based on this new information, the family became more active in Mr. J's care, intervening with the hospital medical staff. Because there was no communication between Mr. J's physician and caseworker, his sister had responsibility for coordinating information and decision-making between the HMO and the ASO. Mr. J's sister requested that a psychiatrist specializing in HIV-related neuropsychiatric disorders outside of the HMO system be allowed to examine her brother. After the hospital refused the request, a case conference was held. The HMO then permitted an outside HIV neuropsychiatric specialist to examine Mr. J. Soon after the examination, a new CAT scan was ordered. Mr. J was placed on an alternative anti-psychotic and other psychoactive medications to deal with the symptoms of HIV-related dementia.

Barriers to Care

1. Breakdown of communication between primary care physician and community-based caseworker;
2. Provider's lack of expertise concerning HIV/AIDS care and treatment;
3. Client's/family's lack of familiarity with HIV-related treatment and complications;

4. Inability of family to offer adequate support due to another chronic family illness; and
5. The CBO lacked clinically-trained staff to establish a professional partnership with the primary care physician responsible for Mr. J's care.

Facilitators to Care

1. Caseworker was a strong advocate, and was instrumental in coordinating Mr. J's care, including enrollment in support services, disability claims, housing, etc.;
2. Increased family/sibling role; and
3. The CBO had extensive knowledge of side effects.

Case Study #3

Mrs. K, a 60-year-old Filipina originally from Manila, immigrated to the United States alone in 1980, joining her two adult children already living here. Her marriage ended in divorce shortly after her arrival in the States, and she has no contact with her former husband. She lives with her youngest daughter and her family. Her English language skills are good, but she is more comfortable speaking Tagalog.

Because Mrs. K had been ill for sometime, the daughter with whom she lived, C.S., arranged for a routine physical. During the course of the examination, the physician learned that Mrs. K had stopped eating, lost a great deal of weight, and had been sleeping most of the day. Her daughter reported that this was very uncharacteristic of a woman who for years had been socially and politically active in her local Filipino community. Her physician ordered various diagnostic tests, including an HIV test. Upon learning that she was HIV positive, the physician counseled her and her daughter about HIV, referred them to an infectious disease specialist, and encouraged them to seek counseling and support services.

Mrs. K. was reluctant to seek services through an A&PI CBO because she was very active in the community and feared being recognized by providers, who also supplied case management to many ethnic groups within the A&PI population. C.S. arranged this visit, because she was concerned about continuing to provide care for her mother as she became more symptomatic. Up to this point, C.S. had helped her mother manage her illness, but she was greatly concerned because her mother lacked health insurance and had not worked outside the home. C.S. also was concerned because her mother had strong spiritual beliefs and clearly

preferred indigenous Asian medical care to Western health care. Mrs. K thought that her preference for indigenous Asian medicines precluded her from using Western therapies. C.S. also was worried about how her mother's illness would affect their relationships in the community.

Despite her ailing health, Mrs. K appeared to be coping well. She was well-dressed, pleasant and politely answered questions posed to her by the intake worker. The social worker provided her with HIV educational materials and explained the range of services available at the agency, including medical assistance. When the social worker asked specifically about what she needed, Mrs. K responded, "...nothing -- I just want to feel better." The social worker reassured Mrs. K and her daughter that as her illness progressed and she identified future needs, the agency would assist her.

Barriers to Care

1. Effective communication between A&PI client and care providers was limited because of language differences;
2. Confidentiality in small A&PI communities may limit a person's access to services through A&PI organizations;
3. Client's preference for alternative Asian therapies;
4. Client and daughter (family caregiver) lacked knowledge of AIDS and local AIDS resources;
5. Reliance solely on daughter to manage navigation through the medical care system;
6. Client's denial prevented her from identifying and pursuing her need for treatment and support service options; and
7. No specific care for women at the A&PI center serving primarily gay men.

Facilitators to Care

1. Supportive family willing to assume caregiver role;
2. Knowledgeable provider who referred client to community-based support services;
3. Availability of community-based provider serving A&PIs; and
4. Early diagnosis and referral to infectious disease specialist.

Case Study #4

Mrs. J, a widow whose husband died of AIDS, was born and educated in the United States, and English was her only language.

Mrs. J sought outpatient treatment at a private hospital. After weeks of testing, she was diagnosed with HIV/AIDS and admitted to the HIV ward. She was the only female HIV patient in this ward, which made her feel embarrassed and isolated. In this private hospital, she reported feeling ignored by caregivers and spoken to as if she could neither understand nor speak English.

She asked her family to transfer her to a public hospital, where she assumed there would be other women patients. Mrs. J and her family believed she received more attention at the public facility. Although very busy, the medical team found her case unusual and regularly consulted with her and her family. Unfortunately, her disease was advanced, and she rapidly deteriorated and was placed in the intensive care unit. ICU staff were overworked and had little time for attention beyond her basic needs. She was alert and able to communicate, and was aware that staff had little time to provide care and comfort when her family were not present.

Throughout the course of Mrs. J's illness, neither she nor her family used local HIV support services available to them, such as information about related services, respite care and grief counseling. Her town lacked an A&PI women's AIDS project, which would have best met her specific gender and cultural needs. Mrs. J's support was limited to only her family and close friends, who lacked insight and knowledge in dealing with HIV/AIDS. An experienced AIDS organization could have provided essential information and emotional support to Mrs. J, her family and friends.

Barriers to Care

1. Mrs. J's lack of awareness of her risk for infection, and her failure to seek early diagnosis and treatment;
2. Cultural stereotypes - hospital staff's assumption that Asians neither speak nor understand English;
3. Lack of appropriate care and insensitivity - placing Mrs. J in an all-male HIV ward, where she felt very uncomfortable and embarrassed;
4. Overworked staff; and
5. Lack of specific HIV services for A&PI women.

Facilitators to Care

1. Supportive and responsive family and friends; and
2. Physicians at public hospital were responsive to her critical care needs and consulted with Mrs. J and her family members.

Recommendations for Technical Assistance

In break-out groups and general discussion, the case studies were further explored and barriers identified. The entire group then reached consensus on recommendations in three categories: technical assistance, policy, and evaluation. The recommendations, listed below, were forwarded to HRSA by the work group. It is expected that these insights and information about distinctive characteristics and needs of A&PI communities will build a stronger partnership between HRSA and A&PI service agencies. The objective is to benefit A&PIs living with HIV/AIDS through enhanced coordination, expanded capacity, and culturally appropriate and linguistically competent services.

- Generally, A&PI ASOs need technical assistance from local, regional, and Federal agencies in capacity-building and institutional development, especially in grant proposal writing, evaluation, program management and strategic long-range planning.
- Technical assistance funds must be made available to A&PI ASOs and other service providers to recruit and hire consultants who can provide sensitivity training to non-A&PI providers. HRSA must allocate funding specifically to conduct cultural sensitivity and competency training among all HIV service organizations whose target population or client base includes A&PIs.
- Technical assistance must be provided to local and State departments of health, A&PI ASOs, community health centers, health clinics and policymakers on using current technology to ensure accurate data reporting on A&PIs living with HIV/AIDS. Specifically, local and State departments of health should receive technical assistance in developing effective and disaggregated data collection systems. These systems must characterize AIDS cases by A&PI ethnicity and other relevant variables, including country of origin and primary language.
- HRSA needs to develop a cultural competency technical assistance project with the following components
 - Formation of a national A&PI work group that would meet periodically to assess and evaluate the cultural competency project

and other issues relating to HIV care for A&PIs, including CARE Act allocation;

- Development of training and resource manuals to provide information on the numerous A&PI cultures and barriers to HIV and general health care;
- Adequate funding to complete the scope of work for this project, including consulting monies to A&PI AIDS service providers for conducting specific training. HRSA is strongly urged to work in partnership with other Federal agencies, such as the Center for Substance Abuse Prevention (CSAP), Center for Substance Abuse Treatment (CSAT), Centers for Disease Control and Prevention (CDC), Office of Minority Health (OMH), and others to pool cultural competency project funds and maximize existing resources;
- Creation of a national A&PI team of experts, recruited from local communities, and comprised of persons living with HIV, youth, women, recovering substance abusers, and gay and bisexual men to pool information and program models in providing HIV care to A&PIs;
- Periodic presentation of case studies on HIV care provision to A&PIs and the methods currently being implemented to carry out those services; and
- Senior Federal officers and staff must be trained in A&PI cultures and issues in order to design Federal programs that are accessible to A&PIs.

Recommendations for Policy

The following policy recommendations were forwarded by work group participants to HRSA as background for addressing barriers to and gaps in HIV care services for A&PIs. These policies focus on the formation of a national A&PI advisory group; provision of additional funding to support programs and services; development of training programs; building networking mechanisms; and others. The objectives of these policy recommendations include: 1) increased relevance of programs to A&PI communities; 2) increased A&PI participation in decision-making processes and the implementation phase of programs spearheaded by HRSA; 3) increased number of A&PIs able to access care and service programs; and 4) increased effectiveness of A&PI and non-A&PI providers in delivering appropriate and effective HIV care to A&PIs and their families. The recommendations are:

- HRSA staff need to establish a permanent A&PI HIV advisory work group to continuously monitor current trends and patterns in HIV care for A&PIs, and how these individuals access and receive needed services. HRSA also must allocate separate and specific funds for the ongoing activities and projects of this advisory work group.
- HRSA must ensure that women advocating for comprehensive HIV-related care services, including A&PI women, be included on decision-making bodies at Federal, State, and local policy levels. ASOs need to create and maintain mechanisms that allow, encourage, and sustain the inclusion and representation of A&PI women in all phases of the decision-making process.
- A&PI youth services must become a local priority. HRSA, through its Special Projects of National Significance (SPNS) program, needs to fund programs that target and serve A&PI adolescents. A&PI advocates need to pressure HRSA and other Federal, State and local organizations to focus on A&PI youth needs regarding HIV prevention, treatment and care.
- HRSA must give top priority to the institutional development of A&PI AIDS and community-based service organizations that are operated by and for A&PIs. Where A&PI organizations are not providing direct service to persons with HIV, HRSA must require that these organizations maintain cooperative relationships with A&PI

community-based service agencies that provide appropriate and sensitive HIV treatment, care and support services.

- HRSA must identify the ten States with the highest concentration of A&PIs, and fund extensive evaluation studies on A&PI patterns of HIV care. Funding must not be based on case numbers and/or surveillance information alone, but should consider other factors such as labor intensity and breadth of services needed and provided. In addition, AIDS case data must be broken down by ethnicity within the A&PI community.
- HRSA must allocate funding for specific training on A&PI issues regarding HIV and AIDS prevention, care and treatment, perhaps through existing AIDS Education and Training Center programs. Program directors, staff, and trainers must receive cultural-sensitivity training focusing on the various cultural, structural and social constraints and challenges faced by A&PI AIDS service providers and A&PIs living with HIV. HRSA can begin to implement this training through the funding and development of a national A&PI cultural competency manual directed towards service providers, funders, policymakers, local, State and Federal government agencies, and CBOs.
- HRSA needs to begin developing A&PI language-specific educational materials, now completely lacking, regarding clinical trials and other forms of treatment therapies currently available. These materials must be disseminated throughout the country and especially to A&PIs living with HIV and their medical care and other service providers. HRSA also must implement a policy to ensure that case management services are provided in the language of the person seeking and receiving the service, and that A&PI ethnic specific providers are used.
- HRSA-funded alternative treatment programs should be made available primarily to A&PIs living with HIV when the treatment is A&PI-based. These therapies should be covered under Title II funds. HRSA must also guarantee access to non-Western primary care, a traditional first line of treatment for many A&PI clients.
- In creating policies regarding service networks, care constellations, and service provision protocols, HRSA and other service providers must take into account the needs and roles of A&PI families of A&PIs living with HIV. Family members must be provided with adequate language-accessible information regarding the care and treatment of their loved ones in order to ensure that they can work side by side with case managers and medical providers.

- HRSA needs to train younger and newer A&PI doctors and other primary care specialists to be sensitive to the needs of A&PIs living with HIV. These medical providers must be encouraged, through incentives, to work in A&PI communities and give priority attention to the health and medical needs of A&PIs living with HIV and AIDS.

Recommendations for Evaluation

Work group participants recommended to HRSA a series of evaluation studies using a three-level analysis. The first would examine the level at which funding is specifically provided to A&PI ASOs. The second level would examine the structure and nature of subcontractual work between mainstream organizations and A&PI-specific HIV service agencies. The third level would study the extent to which service agencies provide appropriate and sensitive services to A&PIs with HIV and AIDS. This would include the development of technical and cultural competency instruments and standards. Evaluation studies need to focus on qualitative and descriptive information to document the comprehensiveness of services needed and received by A&PI clients. The evaluation recommendations are:

- HRSA needs to assess existing comprehensiveness of services for women, including conducting focus groups of A&PI women living with HIV and those caring for persons with HIV. This would address the issue of women-focused services being provided in non-women-based settings such as gay male-identified organizations. A beginning point would be to study HRSA's document on the women's work group. Evaluation priorities already established for female-based HIV care could serve as the basis for creating specifications for A&PI women. HRSA staff and consultants must conduct a literature review and content analysis on current and existing women's services. To address the specific needs and concerns of A&PI lesbian and bisexual women, HRSA must fund and conduct a separate work group. This work group can use a national lesbian health survey currently being conducted as baseline for further recommended evaluation studies.
- HRSA needs to develop guidelines for service delivery to A&PIs living with HIV and AIDS. These guidelines should include standards and protocols regulating how medical providers and community-based service providers work together. Evaluation studies must ask medical professionals if and with which community-based providers they have worked in treating their A&PI clients, and how they are gathering information on their clients' needs and medical/treatment histories.

- HRSA needs to develop a client survey to garner service-user feedback. This survey can be used to identify and measure clients' level of awareness about care and treatment services available, their assessments of the services they receive, and other service needs not currently being met.
- Building on current and past research efforts, HRSA needs to conduct a more descriptive and historical analysis of overall needs of A&PIs, not only regarding HIV care but also about other health care issues. Further, HRSA should fund community-based needs assessment research that examines the knowledge, attitudes, and utilization behaviors of families of people living with HIV. To capture the diverse and complex issues faced by A&PI communities, evaluators and researchers must be provided with cultural awareness and sensitivity training, taking into consideration the wide diversity within the A&PI community and the varying degrees of service utilization among A&PIs living with HIV. This training should incorporate a combination of techniques, e.g., immigration history-taking, interviews with service users and providers, ethnic-specific focus groups, ethnographic studies, and content analysis of existing research literature.
- HRSA needs to evaluate specifically the level at which A&PIs living with HIV access clinical trials. HRSA should assess existing materials and treatment modalities that are available and how information gets to A&PI communities. When community-based service providers use clinical trials as a component of their programs, an evaluation of how they refer and follow up A&PI clients must be conducted. Do these providers acquire informed consent from A&PI clients? Is the information regarding the clinical trials provided in the client's most comfortable language? Is the information about the trial and other drug therapies available in that same language? Is the client provided with options on treatments other than the clinical trial (including complementary therapies)?
- To evaluate the knowledge of A&PI clients regarding treatment issues, community-based service providers must periodically conduct focus groups, surveys, and interviews with their clients. Results must be forwarded to all agency directors and staff and be included in the overall design of programs and services.
- HRSA needs to create nontraditional standards of effectiveness and efficiency. The measure of "service units" or "unit cost per client" is

inappropriate in service delivery to A&PIs. Local, State, regional and Federal agencies must evaluate the comprehensiveness of services being provided instead of total number of clients served. A great need exists to examine the level of productivity among A&PI AIDS service providers, including staffing, time, and services being provided, to gauge the funding needs of these agencies.

- Regarding referral and followup, HRSA needs to evaluate how local health departments refer A&PIs with HIV to community-based service providers. Do local health departments refer these clients to A&PI-identified agencies? How is followup accomplished? Do local health departments have a mechanism to monitor inquiries received from A&PIs? HRSA needs to produce epidemiological studies of rates of infection among A&PI populations in various parts of the country. These studies should contain recommendations on changing AIDS data collected by HRSA grantees and health departments to include ethnographic identifiers such ethnicity, country of origin, language, etc.
- Evaluation studies need to be conducted on the role of the family in service and care provision for A&PIs living with HIV. A descriptive analysis on the role of family support networks, considering acculturation and cultural-specific service being provided (e.g., meals, alternative therapies, etc.), can provide important information to community-based and medical service providers that might enable them to incorporate clients' families into the service stream.
- To examine the level and manner in which A&PI ASOs share Federal resources for HIV care, HRSA needs to conduct an evaluation of how monies are being spent to provide appropriate care to A&PIs living with HIV. HRSA should examine how CARE Act money is given to A&PI agencies and mainstream agencies that include A&PIs in the target population in various jurisdictions. The information should be compared to the number of agencies in that city or jurisdiction, local AIDS surveillance data, and the A&PI population base. An evaluation of which A&PI agencies apply for CARE funding and which of these agencies actually receive funding might be illuminating. HRSA should note why certain A&PI agencies are successful or unsuccessful in obtaining CARE funding.

Appendix A-1

1990 U.S. Census Reporting: Categories for Asian and Pacific Islanders

Asian

Chinese
Filipino
Japanese
Asian Indian
Korean
Vietnamese
Cambodian
Hmong
Laotian
Thai

Other Asian

Bangladeshi
Bhutanese
Borneo
Celebesian
Ceram
Indochinese
Indonesian
Iwo-Jiman
Javanese
Malayan
Maldivian
Nepali
Okinawan
Pakistani
Sikkim
Singaporean
Sri Lankan
Sumatran

Asian, not specified

Pacific Islander

Hawaiian
Samoan
Guamanian

Other Pacific Islander

Carolinian
Fijian
Kosraean
Melanesian
Micronesian
Northern Marian Islander
Palauan
Papua New Guinean
Ponapean (Pohnpeian)
Polynesian
Solomon Islander
Tahitian
Tarawa Islander
Tongan
Trukese (Chuukese)
Yapese

Pacific Islander, not specified

Appendix A-2

Asian and Pacific Islander Service Providers

The following agencies work with or have devoted a large proportion of their overall agency budget to HIV/AIDS programs targeting clients who are Asians, Southeast Asians or Pacific Islanders. They are in alphabetical order, divided by region, and include a telephone number.

CALIFORNIA

<i>Project Name</i>	<i>Phone</i>	<i>Service Area</i>
Asian Advocacy Project	415/499-1476	Marin (Northern Calif.)
Asian American Communities Against AIDS	415/563-0553	San Francisco
Asian Americans for Community Involvement	408/452-5151	San Jose
Asian AIDS Project	415/227-0946	San Francisco
Asian/Pacific AIDS Coalition	415/243-8909	San Francisco Bay Area
Asian Health Services - AIDS Program	510/444-2437	Oakland
Center for Southeast Asian Refugee & Resettlement	415/885-2743	San Francisco
Filipino AIDS Hotline	1-800-FIL-AIDS	Northern Calif. ONLY
Filipino Task Force on AIDS - Northern	415/703-9880	San Francisco Bay Area
Living Well Project	415/575-3939	San Francisco
APLA-Asian Pacific AIDS Education Project	213/962-1600	Los Angeles
Asian Pacific AIDS Intervention Team	213/484-0389	Los Angeles
Asian American Drug Abuse Program Inc.	213/293-6284	Los Angeles

EASTERN/MIDWESTERN STATES

Asians & Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA)	212/620-7287 212/627-5598 (TTY)	New York City
Critical Path AIDS Project	215/545-2212	Philadelphia
Asian American AIDS Foundation	312/784-1310	Chicago
Indochinese Community Center	202/462-4330	Washington, DC
Korean Community Services Center	202/882-8270	Washington, DC
National Minority AIDS Council	202/544-1076	Washington, DC

HAWAII

Governor's Committee on HIV/AIDS	808/586-8110	Hawaii
Hawaii State Department of Health	808/243-5334	Maui
Kokua Kalihi Valley Health Center	808/848-0976	Honolulu
Malama Pono - Kauai AIDS Project	808/822-0878	Kauai
University of Hawaii AIDS Education Project	808/941-6322	Honolulu
Waianae Coast Comprehensive Health	808/696-1525	Waianae

NORTHWESTERN STATES

Asian Pacific AIDS Council	206/386-2532	Seattle, Washington
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Appendix A-3

BARRIERS TO RYAN WHITE HIV CARE FOR ASIANS & PACIFIC ISLANDERS: A WORK GROUP

Health Resources and Services Administration
Bureau of Health Resources Development
Office of Science and Epidemiology

Barcelo Washington Hotel
2121 P Street, N.W.
Washington, D.C. 20037

May 9-10, 1994

AGENDA

Monday, May 9

8:30-8:45 am	Welcome and Introductions (Moses Pounds)
8:45-9:15 am	Discussion of Objectives and Logistics for the Work Group (Moses Pounds and Steve Lew)
9:15-9:45 am	Discussion of Barriers to Access Issues (Steve Lew)
10:00-10:15 am	Break
10:15 am-12:30 pm	Identification of Barriers to Care Issues for Break-Out Groups and Assignment of Participants to Break-Out Groups
12:30-1:30 pm	Lunch
1:45-5:00 pm	Reconvene in Break-Out Groups to Design Evaluation Studies

Tuesday, May 10

- | | |
|-----------------|---|
| 8:30 am-2:30 pm | Break-Out Groups Continue Deliberations
(Participants and staff) |
| 3:30-5:00 pm | Report of Break-Out Groups' Draft
Evaluation Studies
(Federal and non-Federal HIV/AIDS agencies
will attend) |
| 5:00-5:15 pm | Closing Remarks and Departure |

Appendix A-4

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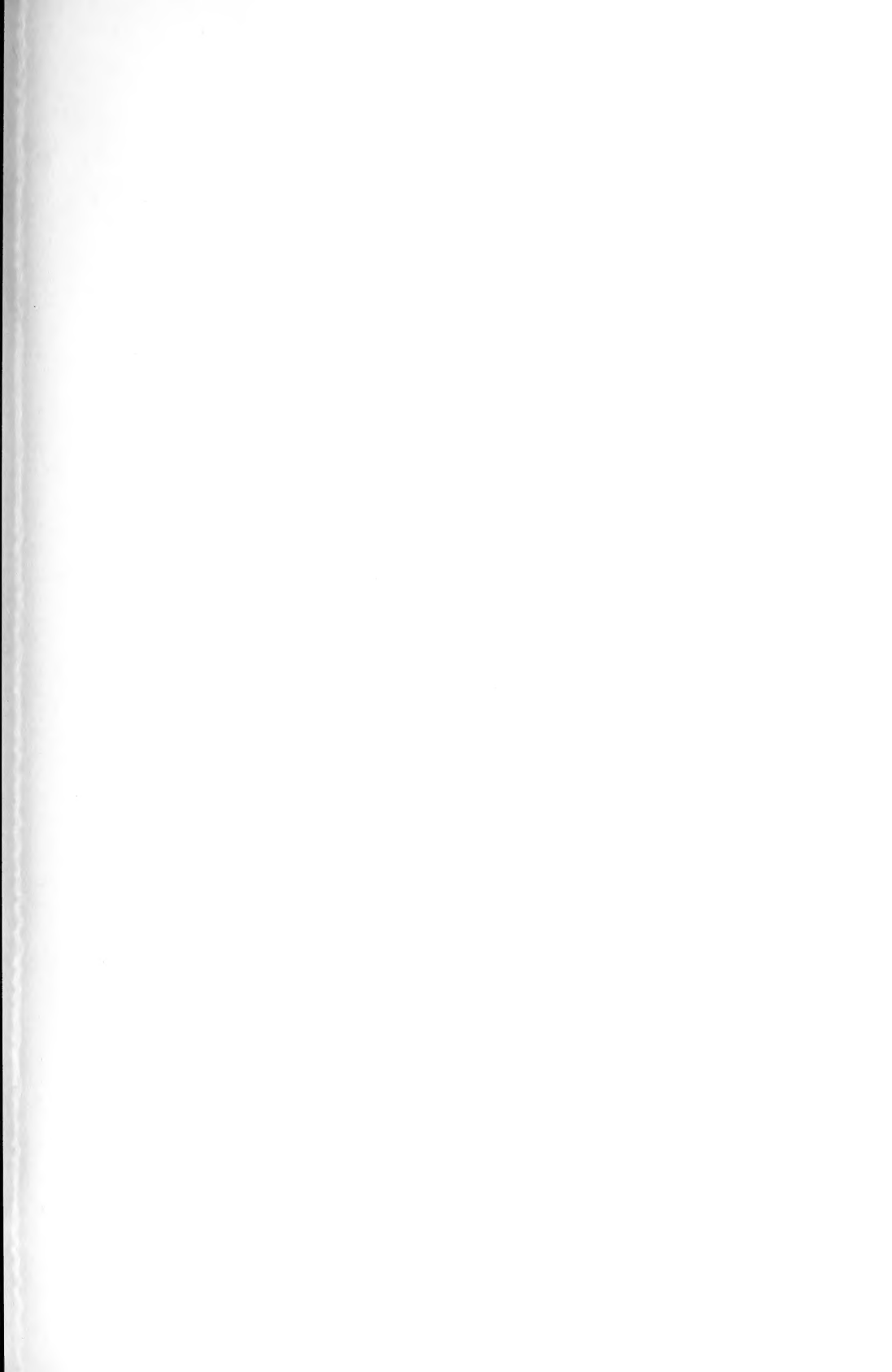
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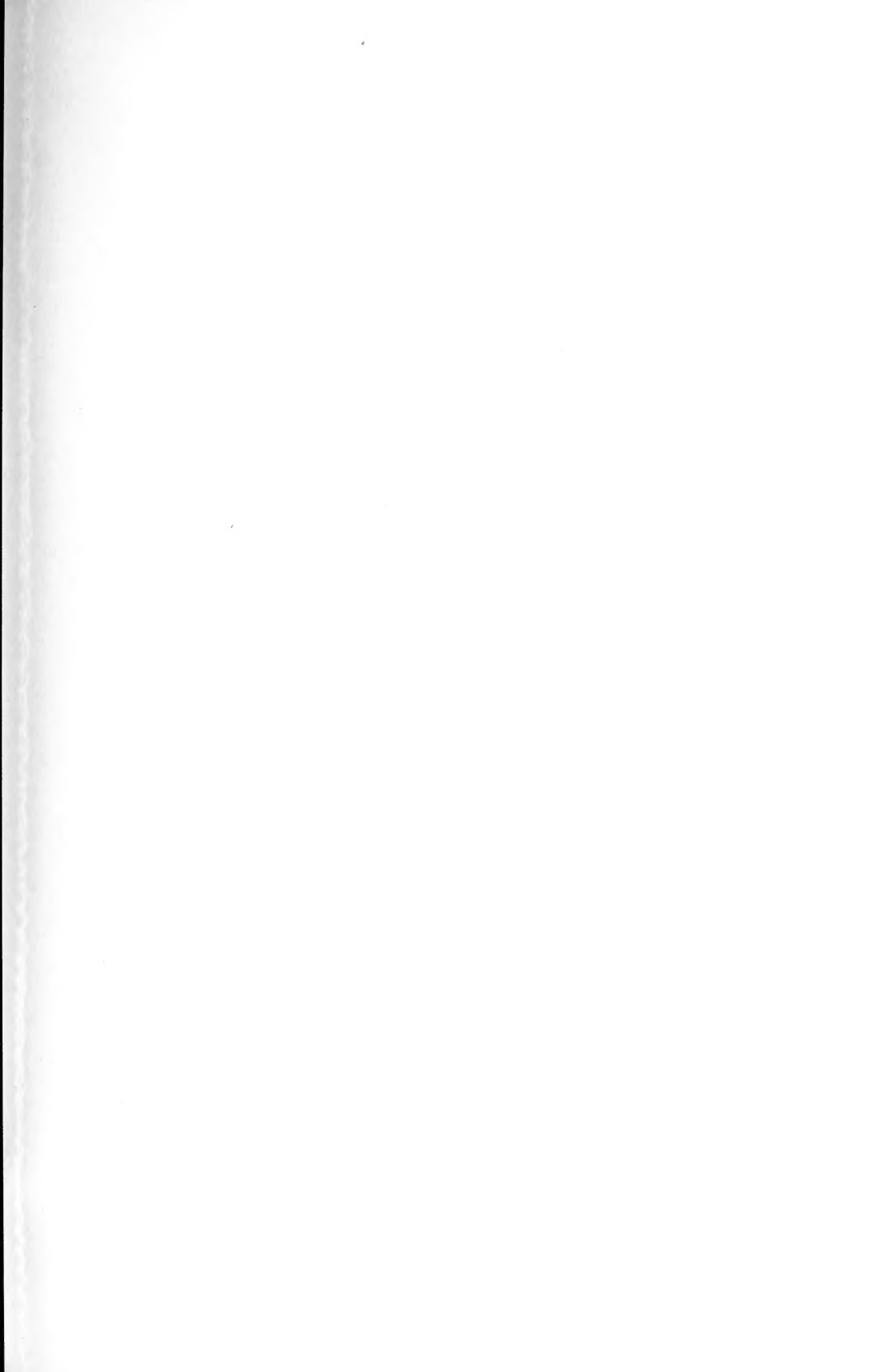
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U.S. Department of Health and Human Services
Public Health Service
Health Resources and Services Administration
Bureau of Health Resources Development
DHHS Publication No. HRSA-RD-SP-95-5